

The Situation of People with Complex Dependency Needs in Europe



Inclusion Europe



Report

Inclusion Europe and its 40 members in these 29 countries are fighting for the rights of people with intellectual disability and their families:

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Introduction

Since several years, Inclusion Europe and its member societies have put an accent on self-advocacy of persons with intellectual disability. For too long parents and professionals saw persons with intellectual disability only from the angle of their disability. We have spoken for them, decided what was good for them and have sometimes forgotten that they are full citizens with own desires. Self-advocates now claim the right to talk, to be listened to and to decide their own future.

But what about those who are not able to claim their rights, who cannot represent themselves, either because they do not have access to verbal language or because of their relational or intellectual difficulties?

We are addressing this group of persons under the name of “persons with severe and/or multiple disability” or “people with complex dependency needs”. They are at risk to become “the excluded amongst the excluded”, as expressed in the subtitle of a reference document published by the European Disability Forum.

In this publication Inclusion Europe wants to describe their situation in different European countries and to analyse the degree of satisfaction for the persons themselves, for the families and also for the professionals working with them.

To collect this data, we have used a questionnaire to all member associations of Inclusion Europe. Replies were received from Germany (Dr. E. Wacker), Belgium (E. Renard, Association AP3), Spain (FEAPS), France (UNAPEI – Polyhandicap group), United Kingdom (Mencap), Ireland (Cope Foundation), Lithuania (D. Migaliova, Viltis), Slovenia (T. Jereb) and Sweden (E. Johansson). We also collected examples of good practice. Space only permits to present the conclusions regarding the situation as well as some recommendations for the work of Inclusion Europe in the future.

Elaine Johansson has expressed her vision for the future like this: “It is my belief that we parents must be able to entertain visions and dreams for our handicapped children, as well as for our other children. When we found out that our child was handicapped our dreams for her future died. Must it be like that? Both consciously and unconsciously we adapt ourselves to what society has to offer, which is both different and much less for handicapped people than for others. Everyone entertains his or her personal visions and dreams, and visions are no less important for the parents of disabled children.”

I personally hope that this brochure and future activities of Inclusion Europe and its members will raise the awareness of the needs of people with complex dependency needs and their families in European disability policy.

Françoise Jan
President, Inclusion Europe

The Situation of People with Complex Dependency Needs

In the Working Group that carried out the present study, a consensus was reached on the following definition of people with complex dependency needs:

People having a severe disability, often multiple disabilities, associating a severe or profound intellectual disability and physical or sensory impairments, resulting in an extremely restricted autonomy and possibilities of perception, expression and relations.

We can also include in this group very severe relational difficulties without physical impairment, notably severe autism. Very frequently these persons have a form of epilepsy, which in 20 to 25% of the cases is difficult to stabilise.

Complex dependency also implies a permanent need of assistance for almost all activities of everyday life. This dependency, however, does of course not deprive these persons of their rights. They are full citizens of their societies and the preoccupation of finding ways for their access to their rights is mentioned in all participating countries.

The situation of children with complex needs

In all countries that replied to the questionnaire, small children have the possibility to use existing structures, like day nurseries or kindergarten. However, these are used in reality only by a small minority whereas the majority of children between birth and six years stay at home with only few weekly interventions.

After six years of age, children with complex needs rarely visit ordinary classes with their friends. Even in Sweden, a country which seems quite advanced in this field, these children go to special classes with specialised teachers in ordinary schools.

In other countries, children with complex dependency needs have to go to special services, sometimes called schools. The data shows that the financing of these structures determines to a certain degree their activities. It would be interesting to compare the education of this group for example in Germany, where financing depends on the regional Ministries of Education, and in France, where it is financed by social security.

Professional training for older children and young people has practically not been mentioned, which seems logical regarding the severity of the disability.

The situation of adults

Living facilities

It seems that in all countries people with complex dependency needs are living mainly with their parents. For example in France, although there are about 20.000 places in services, there are waiting lists everywhere. It can be estimated that at least one in two persons with complex needs is living with the family.

Large institutions for people with complex needs still exist, for example in Germany, Belgium, Ireland, and the United Kingdom. However, significant efforts are under way to close them down. It will be important to accompany this process with a critical eye to ensure that these changes are not only cosmetic, but that existing large structures are really abolished. In Central and Eastern Europe there are still many large residential institutions, often with inhuman conditions. It is one of the main objectives of Inclusion Europe to ensure and safeguard in the enlargement process of the European Union the Human Rights of the people living in these institutions.

In France, people with complex dependency needs are mainly living in services called "living homes", some with medical services, or in "specialised homes". They have between 30 and 60 places and are organised in living units of 6 to 8 persons. Most of the time, activities take place within the service, even though different experiences exist with separating living place and activities. But these have to cope with the resistance of the financing institutions who are often against paying for different services for the same person!

Some large institutions in Europe have been replaced by homes of a smaller size, called group homes or individual accommodation. But, the latter solution seems only very rarely to concern people with severe and/or multiple disability.

Day activities

Activities mainly take place in day care centres and are quite varied: several forms of artistic or bodily expression, listening to music, cooking, birthday parties, swimming, horse riding, activities in nature, etc.

In Germany, some persons with complex needs are working in workshops together with other, less disabled persons, but that seems to be an exception. These activities, as it is also the case for leisure and holidays, are done in groups of disabled persons or sometimes even with non-disabled persons, but always with adequate support persons.

Parents often prefer services organised by parent's associations or other private services and not the public services, because:

- they recognise the lack of specific training of the professionals of public

services and often even a complete lack of knowledge about the needs and difficulties of persons with complex needs;

- the often changing personnel in these services does not allow to establish a satisfactory relationship with the accompanied persons.

However, the number of needed places in day centres exceeds by far the number of places presently available. This fact has been mentioned often in connection with the satisfaction of the families. We can conclude that many of these persons are still at home for the whole day!

Sexual life

Regarding the possibility for persons with complex needs to have a sexual life, the answers give a contrasting picture. Unfortunately, not much detailed information is available on this subject. Spain and Belgium mentioned a double-sided approach to the question: individual sexuality, management of the sexual drive, problems with masturbation etc. on the one hand, and on the other hand relations with others and affective life, certainly possible in some cases, but a dangerous area where abuses and sexual violence can occur. Considerations about this subject are in progress in several organisations.

Financial support and resources

People with complex dependency needs can obtain in all EU countries the necessary support, but often they have to pay much by themselves when they use services or living facilities. For example, a person living in a specialised home in France only receives about 70 euro per month for clothes, personal belongings, leisure, transport and holidays. Germany gives support for different needs like housing, technical support, clothes, leisure time etc., but the person does not seem to have any freedom in managing the budget.

The situation of financial support and budget is changing in several European countries with the introduction of "personal budgets". It will be interesting to analyse the results of these experiences.

Satisfaction with the present situation

In the United Kingdom, methods are developed to better understand if people with complex dependency needs are satisfied with their situation or not. The problem is often to communicate with them in an efficient way. Often, their body communicates and one can read satisfaction in their eyes or in the relaxation of the body. On the other hand, behaviour problems could indicate that the person is not happy with the situation.

Families of people with complex needs are almost never satisfied with the

availability of necessary services. This is the case in France, where families are generally satisfied when the adult is living in a home or specialised service, but where a very large number of other families have practically no support at all. It is the rule of everything or nothing, because temporary services, respite care or support at home to allow families to have a break, rarely exist. The parents of children with multiple disabilities are actually mobilising themselves in France because the insufficient or sometimes non-existing support services are putting these families in situations of total distress. Very often the mother has to stop working in order to care for the child because nobody else could take care and travelling with the child is often very difficult. So the mothers find themselves often completely isolated and marginalised.

Several countries point out important differences in the existence and number of services according to the region. The situation could soon get worse, because the longer life expectation counts also for people with severe disabilities and their number is thus increasing.

Another problem experienced by families and professionals is the lack of training of these professionals. Research has brought about huge progress in the knowledge of disabilities and their functional consequences and in the development of support technologies in all areas. But neither the training of personnel, nor the financing of these new technologies has followed.

Families and professionals are aware of the progress through the media, but do not have access to them and this leads to many frustrations. Furthermore, professionals often do not feel appreciated. They are included in the often negative view of society towards people with complex dependency needs.

Facing this reality, we have to ask what actions could and should be taken in order to improve the situation.

In November 1998, in the framework of the European project EUFORPOLY (1) a "Manifesto of the Rights of People with Multiple Disabilities, their Families and Support Persons" has been proclaimed. This manifesto, of which an extract is included in the annex, should be the guideline for our actions towards these persons and it has largely inspired our recommendations.

(1) Project EUFORPOLY (Europe Training Multiple Disabilities) 1996-1998: Research in partnership with parents and professionals on the support of people with multiple disabilities and the training of this accompaniment.

Recommendations

Each person has dignity and equal value and the way we consider people with complex dependency needs must be a way of valuing their potentials, understanding their wishes and helping them the best we can in their difficulties.

Early support

Early parental guidance is necessary as soon as the disability has been announced to the family. The parents must be psychologically and practically supported and trained to accomplish the every day care of their child. This kind of child frequently shows nutritional disorders of swallowing, insufficient breathing, etc. Multidisciplinary teams must be developed, but on the other hand the child has to be integrated in normal structures of early childhood wherever possible.

During childhood

After four or five years of age, day care centres close to home must be available, allowing the child to socialise without being separated from the family. These small structures must give children, and afterwards adolescents, all opportunities to fully develop their capacities. They must be in contact with normal structures as much as possible, to allow common activities and to make people more familiar with severely disabled persons. Belgium highlights the richness and interest of those heterogeneous groups, the variety of places and persons enriching the experiences. Flexible temporary accommodation should allow the families to have a break from time to time and to spend more time with the rest of the family. Services must be sufficiently diversified in order to respect the choice of the families, and later of the young adults regarding their way of living.

During adulthood

Young adults must have the possibility to choose their own way of living and support services have to respect this choice. They must also have the possibility to choose their activities, if the severity of the disability is not preventing it. They must benefit of sufficient resources to join activities considered as “normal” and which are physically accessible to them. Whenever possible, their opinion has to be asked about any decision concerning their lives.

The implementation of the latter needs the development of training and methods to allow a real communication with people having complex dependency needs. Professionals and parents have to fully trust each other and also the disabled person. Parents often have a very subtle knowledge about

the reactions and behaviour of their child and can interpret them. A good dialogue with professionals can only be very fruitful for them.

A last, very important point is to achieve a change in society's view on these persons and for that people must get to know them and see them wherever possible. Means of support are needed for this and we must claim them! People with severe disabilities have been for too long forgotten and they must now become a priority on the social policy agenda.

Inclusion Europe's Action Plan

For the implementation of Article 13 of the Amsterdam Treaty on non-discrimination, Inclusion Europe campaigns with the European disability movement for a specific disability Directive in order to complement the Directive on employment. Inclusion Europe will make sure that severely disabled people are included in this Directive.

Disability must be seen from a Human Rights perspective and all European countries have signed the European Convention on Human Rights and are obliged to respect it. Inclusion Europe will collect abuses and breaches of the rights people with severe disabilities and systematically inform the general public about them. If rights guaranteed by the European Social Charter are concerned, we will analyse the possibilities of introducing a complaint.

Moreover, Inclusion Europe will stimulate and support exchange of information between its members on good practices, which do not necessarily cost more than the bad ones! This will be important for Inclusion Europe's member organisations in their actions towards their public authorities.

Inclusion Europe will also develop a resource document including practical advice on the needs and abilities of persons with complex needs. It will also include information about possibilities to include this group of persons in activities and projects at local, national and European level. This Resource Document will be aimed at self-advocates as well as at parents and disability organisations to make it easier for them to represent and include the interests of persons with complex needs in their activities.

Finally, Inclusion Europe will take advantage of the European Year of People with Disabilities 2003 to put forward people with severe disabilities in all events, to make them visible and to show their joy in life.

Good practice

The residential association called Kikås – The home of my daughter Pia

(Elaine Johansson, FUB, Sweden)

My dream has actually come true because I have started a parent-run residential association together with three other parents. This is one of many examples where the fight of parents has succeeded to provide good living conditions for their child with intellectual disabilities.

At the moment there are three persons with multiple and severe intellectual disability living in the house. Every person has an apartment of his or her own. Each apartment has a direct entrance from outside, a fully equipped kitchen, a living room, bedroom and a big toilet. My daughter has the contract to her own apartment and pays her own rent. In Pia's apartment my husband and I could help her to select carpets, wallpaper and tiling, while the Board of the Association was selected such articles for the communal premises.

Supported by the Social Insurance Office I recruited three assistants for Pia and prepared a schedule to suit her requirements. I act as supervisor for these assistants while the Association acts as employer.

The first assistant wakes Pia, gets her out of bed and washes and dresses her. She eats breakfast at her own kitchen table. A minibus drives Pia and her assistant to a day centre, where Pia stays until 15:30. She is then driven home where the second assistant is waiting. When Pia returns the assistant can unlock the door to her apartment with Pia's key. Personal integrity is of key importance. No one may enter Pia's apartment in her absence.

The assistant does the dishes, washes Pia's clothes, cleans the apartment and helps to prepare food, in other words what Pia would do if she were not so severely handicapped. Pia can eat with the group or in her own apartment. Pia indicates her choice by showing how she feels and if she appears irritated or in any other way shows that she wants peace, the assistant will fetch food and they eat together in Pia's apartment.

At night various alarms are connected to the apartments. Pia, with her severe epilepsy, has a device which sounds an alarm shortly after the onset of a fit to a receiver borne by a member of the night staff. By this means Pia can get help when she needs it. The other young people have another form of alarm, which is activated when feet are placed on the bedside mat.

Pia has been able, with my help, to choose her home, her companions and her personal assistants. Whether the staff will be permanently employed after their probation period depends on how Pia feels about them. It will be her reactions and satisfaction that will be the deciding factor. It is of great value that Pia has made her own choice and that the personal assistants have been specially chosen.

It is my hope that more and more parents will be able to realise their dream, as I have been able, to see their children in a good home.

Extracts from the Manifesto on the rights of the people with multiple disabilities, their families and their support persons

(Members of the European Union project Leonardo da Vinci EUFORPOLY, Lisbon, November 1998)

I Persons with multiple disabilities have the right to:

- I.1 be treated as full citizens and to benefit from a quality of life allowing personal and social growth with the rights proclaimed by the United Nations...
- I.2 receive medical and therapeutic care adapted to their specific needs.
- I.3 benefit from an education adapted to their developmental potential.
- I.4 to be considered as full citizens with the same Civil Rights as any other member of society, including the right to live.
- I.5 have a private and social life in an environment which is perfectly adapted to their needs.
- I.6 be included in the community to be able to have access to the social, cultural and religious life of this community.
- I.7. be protected against all physical or sexual abuse or other forms of exploitation.
- I.8 be protected against non-appropriate exploitation in the field of medical and social research.

II Parents having a son or a daughter with multiple disabilities have the right to:

- II.1 be respected as full citizens, having wishes and needs like any other responsible person.
- II.2 be respected and listened to by professionals and "politicians" as parents having an intimate and profound knowledge of the needs of their child.
- II.3 receive from the professionals all necessary information in a transparent and respectful way.
- II.4 receive the support allowing them to satisfy their needs in order to be able, if they wish, to raise their child at home, while continuing to satisfy the needs of the rest of the enlarged family.
- II.5 be relieved from their role of parents when necessary and be able to take a break, helping them to continue their role of parents and avoiding exhaustion.
- II.6 decide when their child should leave home to live somewhere else.
- II.7 to be supported in their steps to build up groups or associations, giving them the power to influence positively the life of their child and that of their own family.
- II.8 receive information and training from professionals concerning their specific needs.
- II.9 have a well-balanced and satisfying family-life.

Inclusion Europe

The European Association of Societies
of Persons with Intellectual Disability
and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disability and their families. Our members are national organisations from 29 countries in Europe.

People with intellectual disability are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

People with intellectual disability have many gifts and abilities. They also have special needs. They need a choice of services to support their needs.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disability
- Inclusion in society
- Non-discrimination

Inclusion Europe co-ordinates activities in many European countries, including conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disability. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.



Supported by the European Commission



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